COMMUNITY SERVICES ASSESSMENT DATA

LATINO ASSESSMENT

AFRICAN AMERICAN ASSESSMENT

INJECTION DRUG USER ASSESSMENT

YOUTH ASSESSMENT

PANHANDLE NATIVE AMERICAN ASSESSMENT

NATIVE AMERICAN ASSESSMENT

MEN WHO HAVE SEX WITH MEN (MSM) ASSESSMENT

REGIONAL ASSESSMENTS

REGIONAL ASSESSMENT OF PEOPLE LIVING WITH AIDS (PLWA)

SURVEY OF PEOPLE LIVING WITH HIV/AIDS IN NEBRASKA

RYAN WHITE CLIENT SATISFACTION SURVEY

HOUSING SURVEY OF HIV POSITIVE PERSONS

NEBRASKA HIV/AIDS HOUSING PLAN

STATEWIDE COORDINATED STATEMENT OF NEED (SCSN)

COMMUNITY SERVICES ASSESSMENT DATA

During 1999 - 2003, several assessments were completed, including Latino, African American, Injection Drug Use, Youth, Native American, Men Who Have Sex With Men, Ryan White, PLWA, housing needs, and regional groups.

LATINO ASSESSMENT

Emilia González-Clements, using the Rapid Assessment, Response and Evaluation (RARE) model, completed the Latino Assessment. The RARE model was adapted to fit the unique population of rural, mobile, possibly undocumented, immigrant Latinos living in a large state, and to fit Nebraska. Due to the uncertain immigration status of some of the Latinos, and the extreme sensitivity of the topic of HIV, the research team created a "culture broker" group of 5 individuals to help the team reach the Latinos. The “brokers” are individuals trusted by the immigrant Latino population.

The purpose of the Latino Assessment was to discover information about at-risk Latinos concerning beliefs and behaviors with consequences relevant to HIV infection. This information could be used as a basis for developing prevention intervention strategies.

The Latino Assessment was conducted with immigrant Latinos in Norfolk, Grand Island, and the South Sioux City area. These are communities in Nebraska where there has been an influx of Latinos over the past ten years. Even though the population of Latinos in Nebraska is small, there has been an increase of over 250%, according to the 2000 Census.

The model used seeks information that describes the people, times, places, and socio-cultural processes of HIV risk-taking and protective behaviors. Key research questions included:

- Who are the key vulnerable groups?
- What are their exact risk behaviors?
- Where do these risks occur?
- When? (extent, frequency, time pattern)
- Why do individuals engage in risk behaviors? (beliefs, knowledge, values)
- How can risks be avoided or reduced?

There were several levels of “findings”. In the findings about immigrant Latinos, there are three main sets of factors relevant to HIV infection:

1. Cultural beliefs and behaviors, including gender roles
2. Situational factors, such as poverty and undocumented status
3. Social factors, such as cross-cultural interactions in health care delivery

Latino cultures do not generally recognize “gay” men. Male and female roles, while changing, are specific about sexual activity and consequences. The “macho” ideal allows men more freedom socially and sexually. Religious teachings, whether Roman Catholic or evangelical, are specific about roles and activities of the genders, and do not condone “gay” behaviors. MSM activity may not be seen as homosexual behavior, but may occur because of situational factors such as being alone in a new country.

Two cultural characteristics, embarrassment and shame (concerning talk about sexual topics), and the reluctance to disclose easily to non-family members, must be taken into account for prevention interventions. Two other important issues are the lack of focus on preventive health, and the freedom of expendable income (facilitates drug use).

As part of the Latino Assessment, a special questionnaire that focused on the state of HIV and services in Nebraska was given to the Crisis Response Team. Five findings are especially significant:

1. There is denial in Nebraska communities about HIV in general.
2. The immigrant Latino population is not generally knowledgeable about HIV, transmission, services, etc.
3. Some health care workers need training in HIV/AIDS information and services.
4. Language is a serious barrier to information and services.
5. Prevention strategies must include the substance abuse context.

Generally, intervention strategies should be developed to include other social issues (such as poverty), and be integrated with community based organizations (not just health care specific locations), deal with “settling in” issues, and be consistent and long term.

An ideal is for Latinos to connect with someone who is bilingual/bicultural that can provide information and services. Research data indicate that immigrant Latinos fear rejection by their cultural community, and when they seek assistance, often travel to another town to protect their confidentiality.

What follows is a summary of the findings in the research that was conducted on immigrant Latinos in Norfolk, Grand Island, and South Sioux City. It should be noted that during the research, it was often stressed that everyone is at risk.

Who is vulnerable?

Norfolk: females, promiscuous males, youth, drug and alcohol users, homosexuals
Grand Island: teens, young males, substance users, some females
South Sioux City: MSM, single males, youth, heterosexual females

Risk behavior

Norfolk: drug (methamphetamine, cocaine, marijuana) and alcohol abuse among all age groups
Grand Island: drug (methamphetamine, cocaine, heroin) and alcohol abuse, unprotected and anal sex
South Sioux City: unprotected sex with both male and female, females having sex with partner with other partners, youth having anal sex that is considered "virgin sex", females selling sex for money or drugs, young Latinas seek older males because of status it affords them, drug (methamphetamine, marijuana, inhalants) and alcohol abuse

Where / When it occurs

Norfolk: homes, certain streets, certain parks, empty lots, packing plant, certain bars, summertime is most active time
Grand Island: city parks, many bars, homes, certain parking lot, truck plaza, certain streets, weekends, summertime and payday most active
South Sioux City: bars, dance halls, parks, swimming pools, homes, IBP, parking lots, not seasonal but mostly at night

Why engage in risk behaviors

Norfolk: youth feel invincible, lots of ignorance about HIV, attitude that "it doesn't happen here or to me", curiosity about sex, peer pressure, loneliness, boredom, lack of self esteem, lack of education, not sober enough to make safe decision, machismo idea of conquest
Grand Island: lack of awareness and knowledge, loneliness, feeling of invincibility, addictions, stress, language
South Sioux City: do not know their behaviors are placing them at risk or don't care, "it won't happen to me" attitude, Latino "machismo", loneliness, substance abuse, depression, females have little control in their relationships, female behaviors may be due to economic need, language barrier, underlying beliefs, social rules within community

How to avoid or reduce risk

Norfolk: comprehensive sex education, support from local hospitals and physicians, more church involvement, cultural education, a Wellness Clinic, more facilities, more research
Grand Island: need for a needle exchange program, education, testing, and counseling, go to homes to teach everything including condom use, use language at a level that can be understood, a community center for immigrants and minorities that provides health education, ESL classes, recreation
South Sioux City: bilingual services and information, need interpreters, bilingual outreach workers to reach migrant workers and transient populations are not currently being reached

During the process of the research for the Latino assessment, populations from the broader community were identified to be at risk. In Norfolk, it was noted that Latinos were not the only population at risk. Other populations at risk included African American youth (especially 12 years and older), MSMs, Native Americans, and IV drug users. Drug and alcohol use was indicated to be a risk behavior across all age groups and ethnicity. In Grand Island, individuals at risk in addition to the Latino population include IV drug users, youth and homosexuals. Abuse of drugs and alcohol is an ever-increasing problem. In the South Sioux City area, populations at risk besides the Latino population include IV drug and alcohol users, youth (from teen to college students), men who have sex with men, Hispanic males (married or single), heterosexual females (either through their partners or by their own activities), and Vietnamese males. Alcohol and drug use and unprotected sex with multiple partners are the most troublesome risk behaviors.

AFRICAN AMERICAN ASSESSMENT

Valda Ford conducted a study of African Americans from February through May 2001 in Omaha. The purpose of the project was to determine the level of knowledge about HIV/AIDS health seeking and risk-taking behaviors in the adult African American community. Two paper and pencil instruments were used: The Condom Knowledge Survey and a Population Based Assessment of African Americans and Health-Seeking Behaviors Regarding HIV/AIDS Questionnaire. Focus groups were also conducted with gay males and female sex workers.

The study found that in the general African American population there is little understanding of the impact HIV/AIDS is having on the African American communities in the United States, let alone in Nebraska. Knowledge of HIV/AIDS by the persons participating in the gay focus group was generally very good. There are many African Americans that do not know how HIV is transmitted, think that there are visible signs that will identify a person with HIV/AIDS, do not know how to properly use a condom, and think that water is sufficient for cleaning needles.

The subject of HIV/AIDS is taboo in the African American community in Omaha. Participants related that many African Americans do not think that HIV will touch their lives and that it is not their problem. This attitude is apparently echoed in some faith communities. There is a fear among gay African American men that seeking information about HIV is not possible without identifying their sexual orientation. Many gay men and female sex workers obtain health related information from magazines, radio, TV, the Internet, friends, family, and the barber or beauty shop. One of the biggest issues identified was confidentiality in the health care setting.

For many African Americans, health care issues are less of a concern than survival. The participants identified that education about sex and HIV/AIDS needed to begin with young people, but must be targeted to all age groups. The education needs to be included in the schools, churches, community organizations and media, and must be culturally appropriate.

INJECTION DRUG USER ASSESSMENT

The Nebraska Community Identification Project (NCIP) was a collaborative community identification project, which utilized the assistance of HIV prevention service providers and substance abuse service providers in contact with injecting drug users (IDU) located in

Nebraska. NCIP was conducted in five areas of the state from April 1999 to April 2001: Central Nebraska (Grand Island, Hastings, Kearney); Omaha; Macy / Niobrara; Western Nebraska (Scottsbluff, Gering); and North Central Nebraska (Norfolk, Columbus). Wendy L. McCarty, MA Ed., Project Coordinator, conducted the overall project in conjunction with the Central Nebraska Council on Alcoholism, Grand Island.

The goal of NCIP was twofold: to identify baseline norms, values and attitudes among IDUs and to collect information for the future planning and development of HIV prevention programs in Nebraska. A survey instrument was developed through Essential Strategies of Denver, Colorado. It consisted of 49 questions and was printed in two versions – one for use with IDUs currently involved with a treatment setting and one for IDUs not involved with a treatment setting and who were currently injecting drugs.

A total of 338 injecting drug users participated in this project, with 161 involved in treatment programs and 177 actively injecting at the time of the interview. Of the 338 participants, 211 were male, 124 were female, and 3 identified as transgender. The majority was white; however, in the Macy / Niobrara project all respondents were Native American. It is interesting to note that in the Omaha project, the majority in treatment were white, while the majority in the active group were African American. Also, 16% of the participants from the Western Nebraska project were Hispanic and 14% of the North Central Nebraska project participants identified as Latino. The average age of the participants was 36 years and the majority had a high school education. Those who were involved in a treatment program typically had received more education than those in the active group.

The majority of participants reported incomes in the $2,000/month range with the exception of Central Nebraska and North Central Nebraska; 50% of participants from these areas reported income levels at or below the poverty level. The majority of participants in the treatment group reported to be married, while there were higher percentages of divorce and separation in the active group. The average number of experiences the participants had had with a treatment setting was three, and the most common types of treatment were Alcoholics Anonymous and Narcotics Anonymous.

The average age of initiating drug use varied according to regions. The average age of initiation was 24 in the Western Nebraska project, 16.5 in Central Nebraska, 28 in Macy/Niobrara, 20 in Omaha, and 19 in North Central Nebraska. In all regions, the most commonly cited reasons for initiating injection drug use was “influence from friends” and curiosity. All regions cited methamphetamine and cocaine as the injecting drugs most used, and the frequency of use was 2-3 times per week and daily. It should be noted that alcohol and marijuana were cited as the most used non-injecting drugs in all regions.

The most frequent source of obtaining needles was by purchasing them from a grocery store or pharmacy, and the second most frequent source was from friends who used drugs. In the Macy/Niobrara group, “diabetics” were cited as the primary source of obtaining their needles.

The majority of participants in all the regions had shared or purchased drugs with someone else and knew others who were injecting drugs in their hometowns. In the active group, however, drug use seemed to be most likely done alone by half of the participants. The majority of the participants stated they knew between 11-19 people in their hometown who injected drugs. The majority of participants in Omaha and Central Nebraska knew 40-49 other

injecting drug users in their hometowns. Homes and apartments were cited as the most frequent places where drug injectors hang out, followed by bars and motels.

In four out of the five regions, the majority of participants had used another person's needles for injecting drugs. The majority of the participants in all regions reported sharing cookers, cotton, or rinse water with someone else, as well as having used substances other than bleach to clean needles.

During the past 12 months, the majority had engaged in sex and the majority had engaged in sex with multiple partners. Condoms for any form of sexual activity (vaginal, anal, or oral) were not favored or used, particularly when engaging in oral sex.

The majority of participants had obtained an HIV test and the majority had tested multiple times. The percentage that had tested for HIV was higher in the treatment group. The most frequent reasons cited for not having been tested were "fear", "don't want to know", and "no need – I'm married". Nine percent of the total participants had tested positive for HIV -– 6 individuals in the treatment group and 24 individuals in the active group. Other diseases most frequently cited as "having been told they have" were Chlamydia, Hepatitis B and C, skin infections related to injection (abscesses, cellulitis), and Gonorrhea.

The majority of participants felt injectors were not informed about HIV risk behaviors and the majority saw the need for more information about HIV risks. Face to face meetings were identified as the best method to deliver this information, followed by pamphlets and an anonymous hotline. The majority of respondents state former injectors, followed by health care workers, were the best people to administer this information to injectors. The majority of participants from all regions felt that they and other injecting drug users would visit a drop-in center to get bleach kits, condoms, and information about preventing HIV and Hepatitis C. Those unwilling to visit a drop-in center cited fear, confidentiality, shame, embarrassment, and lack of trust.

YOUTH ASSESSMENT

Emilia González-Clements, using the Rapid Assessment, Response and Evaluation (RARE) model, completed the Youth Assessment. The RARE model was adapted to fit the unique beliefs and behaviors of the youth population in Nebraska. Youth encompass many cultures and social groups, making them a complex dynamic to study.

The purpose of the Youth Assessment was to discover information about at-risk youth concerning beliefs and behaviors with consequences relevant to HIV infection. This information could be used as a basis for developing prevention intervention strategies.

The Youth Assessment was conducted in Omaha, Lincoln, and the Tri-Cities (Grand Island, Hastings, Kearney). A statewide advisory group was created to define the research communities. Additional communities in the sample include Malcolm, Norfolk, Macy, and Walthill. Over 100 individuals (vulnerable populations, health care workers/agency personnel, and community members) were contacted for participation. Of these, 75 were included in the research and of that, 25 were youth between the ages of 12 and 24.

The model used seeks information that describes the people, times, places, and socio-cultural processes of HIV risk-taking and protective behaviors. Key research questions included:

- Who are the key vulnerable groups?
- What are their exact risk behaviors?
- Where do these risks occur?
- When? (extent, frequency, time pattern)
- Why do individuals engage in risk behaviors? (beliefs, knowledge, values)
- How can risks be avoided or reduced?

There were several levels of "findings". The Crisis Response Team (CRT) responded to a special, added questionnaire that focused on the state of HIV and services in Nebraska. Six findings are especially significant:

1. Because Nebraska is a low incidence state, community members just don't feel AIDS can happen here. Even though it is a low incidence state, it is also a lower knowledge state, and creates the potential for high risk behavior.
2. There is an increase in AIDS cases among youth ages 20-29 which indicates that there was a lot of risk behavior as youth.
3. Youth are mis-educated about HIV in general and risk behavior. For example, there is a lot of belief that oral sex is not sex. Abstinence programs contribute to knowledge deterioration. It is a state law to provide HIV education to youth, but differences in school policy and grade level are instances in which students are not getting the education.
4. The disease is growing faster among youth, women, and minorities, especially young African Americans. There is no national standard for reporting of ethnicity in AIDS surveillance and, therefore, AIDS cases among Native Americans are under-counted.
5. Education is the key when it comes to informing the youth population about the causes and treatments of HIV. Though youth are susceptible, some are getting "prevention burnout" or rebellion.
6. There is a need for culturally specific strategies for the divergent populations found in the state (Latinos, Somalis, and Sudanese).

Youth reported two main risky behaviors and one awareness fact relevant to HIV infection:

- unprotected sex
- multiple sex partners, sex experimenting
- myths that one cannot get infected through unprotected oral sex

There is a definite dichotomy between urban and rural youth in the state regarding HIV and AIDS. The epidemiological data shows that a majority of HIV and AIDS cases are documented in the larger metropolitan areas of the state (i.e. Lincoln and Omaha), followed by the smaller communities, and then the more rural areas. Most people interviewed in rural settings felt that "…it's pretty clean here". A key informant in the same rural community indicated that there were indeed cases present, which perpetuates the feeling in rural communities and the stigma associated with HIV that "we're a close knit community, if someone had it, everyone would know". For the people in settings like this "there is a lot of fear and stigma related to the disease. People who are HIV+ are very reluctant to share any information, and are in a constant state of anxiety".

Another situational factor is poverty and the fact that low-income individuals are more concerned about short term needs and finding ways to satisfy them. Although this does not apply to youth directly, youth who come from low income, poverty stricken homes do not have the advantage of insurance and medical care. Finally, for the population in general, in Nebraska, there is a considerable amount of stigma in the state regarding HIV/AIDS and sexual behavior or other associated risks.

What follows is a summary of the findings in the research that was conducted. It should be noted that during the research, it was often stressed that everyone is at risk.

As mentioned previously, there are many different categories of youth in the state and a majority of youth in general are at risk. The research team found that youth behaviors could be organized in the following categories:

- situational
- sexual
- substance abuse
- psycho-social
- cultural

Under the sub-category "situational", the team found that there are instances of youth at risk because "they have more freedom". This is the case of juniors and seniors in high school and college students who typically do not have any adult supervision. Lack of supervision is also noted with middle and junior high school students, especially on weekends. Children in homes without stable, secure caring families or trusted adults present, which also include homeless, is another group at high risk. Another situation is that of gang initiates where "young women are trying to be a part of a gang by sleeping with male gang members". One last situation is youth found in low income settings, who, besides not being able to afford treatment, preventative care, or insurance, may also have low self esteem. This category of youth is also mentioned in the psycho-social category as well.

Sexual behaviors include any and all engaging in unprotected sex and is not isolated to heterosexual males and females, but also includes gay males who are not protecting themselves. Unprotected sex includes anal, vaginal, and oral. There is a strong belief in the youth community that "oral sex is not sex". Heterosexual males and females are also at risk for other reasons: e.g. "young males that have a lot of partners…and males do not like to use condoms". Another sub-category that is of interest are those engaged in sexual experimentation, which includes sex parties, sharing partners, and a recent trends of bisexuality, especially in young women who "see it as status, it's cool, or identification".

Substance abuse and risk associated among youth includes alcohol and drugs ("drugs are much cheaper and can be cooked anywhere").

The psycho-social characteristics are hard to explain as they lie in the psyche of youth and are not readily visible on the surface, but in their internal behavior. Some of the findings include:

- invincibility among youth: "It can't happen to me"
- bloodletting (includes cutting): "Kids who are depressed engage in intentional slashing. This is treated as severe depression with mental health referrals made and is preventable in this population"
- Scarring and tattooing: "Young people are not depressed and the intent is more decorative than injurious". The problem is that self-tattooing and scarring is done in bathrooms, playgrounds, and hallways; places and tools that are not always sanitary
- Youth with low self esteem, such as "young women in general who use sex to fill a void in their own lives"
- Youth from low income families
- Homeless youth who have no means for preventative care or treatment

Minorities were mentioned in a few cases because "they [may] come from broken or dysfunctional families" and "a lot of African Americans come from single homes, no male role model, and their siblings may come from more than one father".

Exact risk behaviors can be organized into the following categories:

- drugs
- sex
- psychological
- other

Under the category "drugs", there were many illicit substances that youth are taking, including the following:

methamphetamine	IDU (heroin, cocaine, meth)
marijuana	date rape drugs
ecstasy	speed
mushrooms	crack
alcohol	

Sex sub-categories include:

unprotected or unsafe sex	current bisexuality trend
premarital sex	homosexual activity
oral sex	multiple sex partners
not knowing how to use a condom or to negotiate for safe sex	

Psychological categories include:

looking for self esteem
invincibility
games of chance where you can "one up" someone
males not wanting to wear a condom

One informant did mention an important preventative category that youth are not involved in, getting a regular annual checkup.

Risky behavior occurs everywhere. The most often mentioned places were homes, parties, and cars. Informants also offered some more specific locations that are as follows:

- alleys
- pasture parties
- parks
- schools
- truck and rest stops
- "where mom and dad are not"
- skating rinks
- motels
- restrooms
- concerts
- parent's homes (parent may be home)
- shooting galleries
- bars
- abandoned homes/farmhouses
- lakes
- "in the country"
- mall
- dorm rooms
- raves
- elevators
- parking lots

In addition, risky behaviors occur anytime. Some of the more specific times include:

- after school
- nights
- warmer weather or a warm place during cold weather
- weekends when there is more time to socialize
- tied to the time of the month i.e. payday or the first of the month
- 3:30 to 5:30, the timeframe when school is out and parents are still at work
- summer, when school is out and there are more activities
- after any major event such as prom, sports, etc
- school vacations such as spring/fall break
- Friday and Saturday night

Within the youth population, there is an incredible amount of denial, low self esteem issues, and lack of education about HIV and the feeling of invincibility that is, “[HIV] can't happen to me". Some youth do know that there are consequences, but there is also a great deal of ignorance. "People still think they can believe someone if they tell them they are clean". Youth who do know there are consequences maintain the same attitudes because "they feel that they can do anything and they are powerful because their whole life is in their hands" and "they feel they are supermen".

Ironically, peers are the main source of information for youth and peer groups were one of the priority interventions mentioned. However, peer pressure leads to an increased level of risk taking. Informants told the team "peer pressure to fit in", "to gain respect from peers", "to prove to friends", and "we are teens; we’re supposed to do this". Other informants cited social norms, such as drug and alcohol abuse. In fact, some told the team that "alcohol is easier to get than cigarettes" and "sex is everywhere". Finally, "parents may be involved in the same behavior", so sometimes there are not positive influences in the home.

Media plays a very significant role because it is everywhere: billboards, TV, radio, and the Internet. Some comments included, "the media makes it look cool and shows none of the consequences" and "in their childhood, if they see sex on TV or at home they might think it's ok". The media plays an even bigger role for women, as it degrades them (beer commercials) and "there is a lot of pressure on women to look a certain way".

The majority of informants said risks could be avoided or reduced through education. Education by far was the most noted way to reduce the risk associated with HIV. Education in the form of a longer curriculum in the schools, health promotion, peer educators (which promoted youth empowerment) must link HIV education with associated risks, such as drug and alcohol use. There was an extensive discussion from informants on having parents involved in their children's lives and that youth need positive role models, not only in the home, but elsewhere. Education is needed not only in the schools, but also at church, home, and extra-curricular activities.

The curriculum needs to be fun and have a reward. Suggestions include:

- make it real to them
- use a lot of visuals, to see the stages of HIV and AIDS
- be honest about the issues, no sugar coating (i.e. the analogy of the flower to the vagina); tell it like it is.
- find a way to make it personal and build trusting relationships and rapport and find a link between behavior and action
- do not preach, as this can lead to rebellion

Informants felt that education should start early, as early as kindergarten. Additionally, education of youth that oral sex is indeed sex. Teach about the tools needed to protect oneself, as well as education about responsible choices. Make birth control and condoms more available in communities. Finally, rural youth suffer from isolation. By networking youth across the state vis-à-vis an Internet portal that is private, youth can obtain accurate and useful information.

PANHANDLE NATIVE AMERICAN ASSESSMENT

In 2003, Western Community Health Resources (WCHR) conducted a project to increase the number of HIV positive Native Americans accessing medical care in the Nebraska Panhandle. This project was funded through Ryan White Title II Minority AIDS Institute (MAI) funding. WCHR applied for funding for this project in 2002 and at that time, one HIV positive Native American enrolled in the WCHR Ryan White Title III program. As of December 2003, there are three HIV positive Native Americans enrolled in the WCHR Ryan White Title III program.

In the initial proposal, there were three outcomes and eight objectives established. They are as follows:

Outcome Measure #1: Train five (5) Native American cultural gatekeepers in a survey/interview training

Objective #1: Identify and contract with five (5) Native American cultural gatekeepers to participate in the survey/interview training and to conduct surveys with high risk Native Americans

Objective #2: Develop training materials and survey

Outcome Measure #2: Deliver surveys to fifty (50) high risk Native Americans in western Nebraska and surrounding area

Objective #1: Fifty (50) high risk Native Americans will have an increased awareness of the local medical services available to HIV positive individuals and how to access those services

Objective #2: Develop feedback process for completed surveys to be delivered from cultural gatekeepers to project staff

Objective #3: Develop reimbursement process for survey participants

Outcome Measure #3: Increase from one (1) to three (3) the number of HIV positive Native Americans enrolled in the WCHR Ryan White Title III program

Objective #1: Hire a new Outreach Worker with Ryan White Title III funds

Objective #2: Compile information from Phase One and Phase Two surveys and present information to Ryan White Title III Advisory Group and Outreach Worker

Objective #3: Outreach Worker will make 100 contacts with high risk members of the Native American community

A total of 65 high risk Native Americans were surveyed. Of the 65 surveys, 45 were completed in the field by the Native American cultural gatekeepers and 20 were completed in either detox centers or in WCHR offices by WCHR staff. The results from the survey are:

- 37% of those surveyed (24 of 65) said they had traded sex for alcohol and drugs in the past year. Most of this activity was taking place in and around Whiteclay, Nebraska.
- 66% of those surveyed (43 of 65) said they had unprotected sex with multiple partners in the past year. This reflects anecdotal evidence collected in the Panhandle about unprotected sex with multiple partners taking place within the Native American community.
- 11% of those surveyed (7 of 65) said they shared needles with someone in the past year. Of those seven (7), three (3) were men and four (4) were women. None of the men have ever tested for HIV. Three (3) of the four (4) women had tested for HIV.
- 55% (30 of 54) reported they had been tested at least once for HIV.
- 79% of those who reported they had not tested for HIV (19 of 24) said they had not tested because they did not think they needed to be tested.
- 21% of those surveyed (14 of 65) reported they had previously been diagnosed with an STD. 78% of those fourteen (14) reported they have been tested for HIV. It appears then that most individuals who have STDs are also being screened for HIV.

The increased enrollment of Native Americans in the WCHR Ryan White Title III program cannot be attributed solely to this project. However, the efforts of this project to increase awareness of HIV within the Native American community to facilitate access to CARE Services has certainly played a role in the increased enrollment. Discussions with providers, as well as word of mouth within the Native American community, have helped get the word out that HIV positive Native Americans can access quality medical care in western Nebraska.

NATIVE AMERICAN ASSESSMENT

Emilia González-Clements, using the Rapid Assessment, Response and Evaluation (RARE) model, completed the Native American Assessment. The RARE model was adapted to fit the unique beliefs and behaviors of the Native American population of Nebraska.

The purpose of the research is to identify Nebraska's Native populations and their health beliefs and behaviors as background for potential HIV-prevention activities. The resulting report will be utilized by the Interventions Committee of the NHCPC as part of their investigation of potential interventions that are effective and culturally/linguistically appropriate.

The research focused on the Native populations in Nebraska that have tribal headquarters in the state. The four groups are the Santee, the Winnebago, the Omaha, and the Ponca. The Lakota do not have a tribal headquarters in the state. However, due to the signifcant numbers of Lakota living in Nebraska, the project included them as well. According to the 2000 Census, the native population in Nebraska is 22,764 individuals from 128 tribes.

Research methods included key informant interviews, short follow-up surveys, and literature reviews. An important source of information is data provided by national tribal health organizations, such as the AIDS Education & Training Centers National Resource Center (AETC) and National Native American AIDS Prevention Center (NNAAPC).

Four of DSAI's seven researchers were members of local tribes. The other three were applied anthropologists. The research team included a "cultural broker" who provided a native perspective and recommendations for the project. A Tribal Advisory Group (TAG) advised the research team. The TAG is comprised of the tribal medical directors and members of the state health department's Tribal Health Coalition.
Two main issues, the complexity of the study population and the sensitivity of the research topic, dominated the research limitations. After obtaining tribal permission to conduct the research, the team identified the sample populations. The diversity of the Native population immediately became apparent. The initial tribal categories for the samples were not adequate. That is, a sample of "50 Omaha" did not differentiate between those Omaha living on their reservation and urban Omahas, whose beliefs and behaviors may be different. "Omaha" identify is based on decent from an Omaha father, and earlier research report that 45 tribes had married into the Omaha Tribe by 1961. There are many Indian individuals who have a father from one tribe and a mother from another tribe. "Self-identification" is the criteria the team followed, by asking "What's your tribe?", as advised by our cultural brokers. Other issues included trust and cooperation with researchers, mobility of the population, and distrust of use of research findings.

The research included three literature reviews: 1) national native initiatives in HIV prevention, 2) national Native guidelines for working with Natives and HIV, and 3) national information on Native prevention interventions. The goal was to gather information that may be of use with native populations in general because of the 128 tribes represented in Nebraska. Information about the four main Nebraska tribes came from the interviews and conversations with Natives living in Nebraska.

The guidelines included discussions on native values and beliefs important to understanding behaviors and as a framework for prevention. Preliminary findings about Native initiatives in the fight against HIV/AIDS include three models centered around Native values and a locally-replicated methodology for addressing health issues.

Findings of interview data indicate that:

- Colonization and acculturation (impact on a dominant culture on traditional beliefs and behaviors) have and continue to shape Native lives.
- Interventions should be Native-specific, with Native staff.
- There are urban and rural differences among Native populations.
- There is much high-risk behavior, including alcohol abuse.
- There is limited awareness of HIV.
- There is much fear about contacting HIV.
- HIV is seen by some as a “punishment” for “something bad they or their family did.”
- [People] should not talk about an illness or the illness will happen to them.
- Interventions should feature an egalitarian relationship between staff and program participants.
- There are cultural factors important for prevention, including
    - caring for future generations of descendents
    - a feeling of responsibility for the preservation of humanity
    - the role of elders as teachers for youth
- There is a pattern of individuals infected elsewhere returning to the reservation for late stage treatment and to await death.
- Among the Lakota, there is a value of non-interference, which could have implications for interventions.
- The Ponca have experienced greater culture-loss in Nebraska’s Native populations and are more dispersed.
- One-on-one counseling with Native counselors is most effective.
- Omahas still have very traditional values compared to other tribes.
- Native community events are useful for HIV education purposes.
- Native populations include many individuals living in poverty, with its attendant impact.
- “There are ‘a people’ [i.e., a tribe] and some of the people are gay; that is natural.”
- People feel “panic” at the thought of HIV, even health care professionals.

MEN WHO HAVE SEX WITH MEN (MSM) ASSESSMENT

Emilia González-Clements, using the Rapid Assessment, Response and Evaluation (RARE) model, completed the Men Who Have Sex With Men (MSM) Assessment. The RARE model was adapted to fit the unique beliefs and behaviors of the MSM population of Nebraska. MSMs encompass many cultures and social groups, making them a complex dynamic to study.

The purpose of the MSM Assessment was to discover information about at-risk MSMs concerning beliefs and behaviors with consequences relevant to HIV/AIDS infection. This information could be used as a basis for developing prevention intervention strategies.

The MSM Assessment was conducted in Omaha, Lincoln, and the Tri-Cities area (Grand Island, Hastings, Kearney). These communities were chosen from the responses of the telephone surveys to the Crisis Response Team (CRT). Although multiple cities were mentioned, the majority focused on the previously mentioned three communities. These cities not only correlate with the statistics on numbers of HIV/AIDS cases found in these counties, but have also seen a rapid growth in Latino and other minority populations. Finally, these counties provide an even geographic sample of the state, especially in the eastern portion of Nebraska where population density is greater.

The model used seeks information that describes the people, times, places, and socio-cultural processes of HIV risk-taking and protective behaviors. Key research questions included:

- Who are the key vulnerable groups?
- What are their exact risk behaviors?
- Where do these risks occur?
- When? (extent, frequency, time pattern)
- Why do individuals engage in risk behaviors? (beliefs, knowledge, values)
- How can risks be avoided or reduced?

There were several levels of “findings”. The CRT responded to a special, added questionnaire that focused on the state of HIV and services in Nebraska. Five findings are especially significant:

1. "It, (HIV/AIDS) is a big city problem" according to accounts heard by the CRT members. Because Nebraska is a low incidence state, community members just don't feel AIDS can happen here.
2. There is a high degree of stigma in the state with regard to MSMs and sexual behavior.
3. The disease is growing faster among youth, women, and minorities, especially young African Americans. There is no national standard for reporting of ethnicity in AIDS surveillance and, therefore, AIDS cases among Native Americans are under counted.
4. Education is the key when it comes to informing the MSM population about the causes and treatments of HIV, though some are getting "prevention burnout" and are tired of hearing about it all the time.
5. There is a need for culturally specific strategies, as when they are developed, they are usually directed to the white gay community, recreational sex, or the bar scene

MSMs reported two main risky behaviors and one fact relevant to HIV infection:

- Unprotected sex
- Unprotected anal sex
- Knowledge that one can get infected through unprotected oral sex

MSM activity may not be seen as homosexual behavior, but may occur because of situational, social, or cultural factors. Some of these factors include male prostitution, forced to stay in the closet because of the stigma associated with being gay in Nebraska, situational factors such as no "gay sex" occurring in the prison system even though male-male encounters are happening. Another factor is that MSM is a "hidden" culture in that risky behaviors occur at places outside the home such as parks, road side stops, and places that harbor "glory holes".

Intervention strategies should be developed to include other social issues (e.g. poverty), be integrated with community-based organizations (not just health care-specific locations), deal with "settling in" issues, and be consistent and long-term ("7 times to hear a message and lead to action").

Overall knowledge about HIV transmission, treatment, and care is relatively high in the state among the MSM population. But because of the quality of care and advances in medications, AIDS is not talked about as much and the level of awareness has gone down to a point. Youth are aware, but feel the medications will prevent the disease and some feel that you can take certain drugs, like the morning after pill, and will not get infected. The dichotomy in age awareness is also apparent as older MSMs were bombarded with information in the late 1980's and early 1990's and feel that the same level of information is not the same today.

What follows is a summary of the findings in the research that was conducted in Omaha, Lincoln, and the Tri-Cities. It should be noted that during the research, it was often stressed that everyone is at risk.

Who is vulnerable?

Omaha: young people, especially those who have anonymous sex; sex workers; clubbers/ravers/partiers; substance abusers; minorities, especially African Americans, Hispanics, Native Americans, Sudanese; mentally ill; MSMs who don't identify as gay
Lincoln: youth; Latinos; African Americans; Native Americans; MSMs; IV drug users, Sudanese; other
Tri-Cities: youth; IV drug users; MSMs; minority groups, especially Hispanics and African Americans

Risk behavior

Omaha: unprotected oral and anal sex ("barebacking"); drugs: alcohol, cocaine (crack and coke), crank, heroin, meth, and ecstasy; male prostitution; mental illness; anonymous sex
Lincoln: drugs: ecstasy, cocaine, marijuana, meth, alcohol, heroin, mixing Viagra with ecstasy (sextasy); unprotected sex; unprotected anal sex; oral sex and the knowledge of how it is indeed unsafe when unprotected
Tri-Cities: unprotected, anonymous sex; drugs: alcohol and meth; needle-swapping; sex with both males and females; pornography; lack of negotiation skills

Where / When it occurs

Omaha: anywhere; "hotspots": certain parks, downtown bars, truck stops, liquor stores, public bathrooms; hotels where drugs and sex are purchased; home; evenings during spring and summer is the most active time
Lincoln: rest areas on I-80; parks; bars; after hours parties; homes; elementary schools; university bathrooms; cruising areas and prostitution around the Capitol; alleys; glory holes; malls; certain retail and convenience stores; evenings during spring and summer is the most active time
Tri-Cities: parks; restrooms; glory holes; adult bookstores; cruising areas and prostitution; sex parties; bathhouses; college and academic year and in summer months are more active, especially on Friday and Saturday nights

Why engage in risk behaviors

Omaha: it is more pleasurable; they are horny and don't think; under the influence of drugs and alcohol; poor judgment; poor decision making ability for those who are mentally ill; take the risk as a thrill; don't think it is a problem because they haven't seen anyone die of it; pessimistic view of the future
Lincoln: thrill of carnal pleasure; just don’t care; it is not an issue of love but money or a place to spend the night; feel invincible; HIV will not happen to them; societal pressures; may not understand their risky behavior
Tri-Cities: "won't happen to me" attitude; drug/alcohol abuse; increased sexual pleasure and stamina; because they're "closeted" - sexual anxiety; low self esteem - don't care; can't legally marry

How to avoid or reduce risk

Omaha: education; validation for the gay community; reduced stigma; policy changes against discrimination; funding for mental illness; reform in the prison and immigration systems
Lincoln: education; condom distribution and instruction on proper condom use; funding for services; research: cultural, social, medical; fundraising; prevention; testing; use of visual media to relay messages (e.g. graphic posters); changing legislation (e.g. abstinence only, Defense of Marriage Act)
Tri-Cities: more education to all people that is consistent; meetings/peer groups; church and community support for gay/lesbian groups; leader or activist to take charge in the communities to encourage attention to the issues; sexual addiction treatment; publicize the issue some more to "scare the public"; drug/alcohol treatment programs; peer support from peers who are protecting themselves

During the process of the research for the MSM Assessment, populations from the broader community were identified to be at risk. Respondents from all the research areas describe the same risky behaviors, general community denial and disapproval, involvement of alcohol/drug use, and issues of mental illness and sex workers. They also discussed the fatalistic or unrealistic beliefs of young MSMs and the increasing numbers of people of color becoming infected with HIV. They also agree on the negative messages and potential impact of the "Abstinence Only" approach. That is, school children will not get factual information about risks for HIV or information about safe practices.

REGIONAL ASSESSMENTS

From October 2001 through January 2002, assessments were completed in each of the six regions of the state to determine the needs of each region. Individuals that are members of the Regional Community Planning Groups participated in the survey. What follows are the survey results.

Each of the six regions identified needs that are unique for their region related to HIV/AIDS. In the majority of the regions, the following issues were presented:

- People don't understand that HIV is around; there is denial and resistance to education and information; there is lack of education on basic HIV knowledge; social stigma occurs due to ignorance.
- Abstinence Only education in the schools is a problem, as well as the conservative political atmosphere.
- There are cultural and language barriers and many communities are lacking resources for minority populations.
- People have difficulty visiting the testing sites because of confidentiality issues and the stigma associated with HIV.

Each region identified the following needs unique to their region.

<u>Panhandle</u>

- most rural region
- schools have Abstinence Only education
- girls 10-11 years old are getting pregnant
- STD rates continue to increase
- lack of resources for the Native American community

<u>Southwest / Great Plains</u>

- a very large region with no centralized location to meet
- lacking resources for the Hispanic / Latino community

Central
- high incidence of IV drug use, including methamphetamine
- Hepatitis C is skyrocketing
- resources for the Hispanic / Latino community are lacking
- have a large influx of Vietnamese and are lacking resources to work with them

Northern
- need for knowledgeable medical providers, including dentists, that will treat HIV positive people
- lacking resources for Hispanic / Latino, Sudanese, and African American communities

Southeast
- Lincoln is the largest re-settlement community for immigrants in the state, but lack resources for Hispanic / Latino, Sudanese, and African American communities

Midlands
- most heavily populated area of the state and has both urban and rural issues
- have a military community
- high level of prostitution
- high use of illegal drugs
- high minority population, including African American, Native American, Sudanese, Asian, and Hispanic / Latino, with a lack of resources for these populations
- a large unidentified MSM population

Specific categories of information were collected from each regional group. The responses are summarized as follows:

- The majority of the regions reported the following risk behaviors and groups at risk.
  - The teen / adolescent population is having unprotected sex with multiple partners, and using alcohol and illegal drugs. Many teens (as young as 13) are diagnosed with STDs. The teens lack the knowledge about sex, STDs, and HIV. The teens are aware of HIV, but do not think that it is in their community or that it will affect them. They believe that it is "no big deal" to get HIV because there are medications available now for treatment of AIDS.
  - Women having unprotected heterosexual sex. May have a partner that has not disclosed his bisexuality.
  - High use of alcohol and illegal drugs (methamphetamine, cocaine, marijuana, ketamine) in all populations.
  - Men who have sex with men are relaxing their safer sex practices.
  - Heterosexuals recently divorced or widowed individuals 40 to 60 years old having unprotected sex; lacking knowledge of HIV.

- The regions identified the populations most affected, impacted, concerned and/or at risk as:
  - The majority identified school aged youth and teens into the early 20s, Hispanic /Latino males and females, young women, and all MSMs.

- During the assessment, the question was asked: how does culture, language, values, and norms affect the HIV epidemic in this region?
  - The majority of the regions thought that they were not meeting the needs of the Hispanic / Latino population.
  - The Hispanic / Latino culture condones males having sex with males if the wife is not present.
  - Talking openly about sex in the Hispanic / Latino culture is not considered appropriate, and the cultural norms often prevent women from talking with their partners about using a condom.

- Language was found to be a big barrier to education, treatment, and prevention of HIV.
  - Many in the Hispanic / Latino culture do not seek services because they are unable to convey their needs due to the inability to overcome the language barrier.
  - Qualified translators are not available, and it is too embarrassing for family members to serve as translators.
  - There is also a mistrust and lack of confidence in the health care system.
  - When survival is the issue, people are not concerned with issues surrounding the prevention of HIV. Survival is a very real issue for many Hispanic / Latino individuals and families.

- The regional groups were asked what prevention messages will those identified to be at risk listen to, and what is the best way to reach those at risk with messages, aimed at awareness, knowledge, and the need for behavior change?
  - The majority replied that peer educators, role models, and parents should be providing the prevention messages.
  - Prevention education should include the correct information and integrate HIV with other programs, since it is such a controversial subject.
  - Using individuals that are close to the age group and culture that is trying to be impacted, using simple language, getting into the school systems, and utilizing the gatekeepers of the community will help in reaching persons at risk.

- The regional groups were asked about what a prevention program should look like.
  - They believe that the school systems and teachers should be knowledgeable about HIV/AIDS and human sexuality; that parental involvement is extremely important; that women must be empowered to have control over their lives; and that PLWA must become more involved with the education of the community.
  - The prevention programs must be language and culturally sensitive.

- The regional groups believe that there are barriers and gaps that hamper meeting the HIV care and prevention needs in their regions.
  - The gaps and barriers identified include: language, culture, conservative thinking, Abstinence Only policies in the schools, controversy over who should educate the children, and parents believing that their children will not be affected.
  - There is a lack of medical personnel that are trained and knowledgeable about HIV and there is a general lack of knowledge in the community about HIV.

- Individuals who have been engaging in risky behaviors may not want to know whether or not they are infected, or may be in denial, or fear the results and are concerned about confidentiality, so delay getting tested.

➢ In the regions, individuals obtain their HIV education from sources such as the counseling and testing sites, the Nebraska AIDS Project, county health departments, the infectious disease physicians, and the Internet.
  - Most of the regions believed that once diagnosis was made, the education was excellent.
  - There were a few barriers to education including: Abstinence Only policies, lack of a healthy view of sexuality, the mindset that HIV is not in my community, complacency about the fact that there are fewer deaths, parents believing "it won't happen to my child", and availability of information that is culturally and linguistically appropriate.

REGIONAL ASSESSMENT OF PERSONS LIVING WITH AIDS (PLWA)

An assessment of Persons Living with AIDS (PLWA) was conducted from October 2001 through January 2002 in four of the six regions. A total of 27 PLWA, 18 male and 9 female (2 females were adolescents), participated in the assessment.

What are the risk behaviors and who is at risk?

Panhandle: Everybody is at risk. Teens are having casual sex and think nothing of it. Don't have to have a boyfriend or girlfriend to have sex. Many times teens have no discussion about protection before having sex. Drugs and alcohol are available at teen parties.

Southeast: Teens as young as 13 are having unprotected sex. Kids say they don't need to use a condom because they have sex with "clean" people. Use of alcohol and illegal drugs.

Central: Everyone is at risk. Young people have nothing to do, so do drugs, alcohol, and have unprotected sex. MSM just "coming out" raped at party.
Everyone concerned about pregnancy, but not about STDs or HIV. Getting information to kids a problem with Abstinence Only programs in schools.

Northern: Everyone is at risk. Children are at risk if they don't get information about HIV.

How does culture, language, values, and norms affect the HIV epidemic in your region?

Panhandle: Language is an issue. Written materials for Latinos lacking or not up to date. Many faith communities do not accept HIV positive people. Homophobia is alive and well.

Southeast: Little or no HIV educational opportunities for Latinos in their native language. African Americans want to ignore HIV and homosexuality. HIV cannot be discussed in the Catholic church here.

Central: No one wants to talk about HIV. People think HIV doesn't happen in rural areas. Many people believe that HIV is someone else's problem and that HIV is just a "gay" disease.

Northern: Lack of medical personnel that understand and speak Spanish. There is a strong religious community that looks upon individuals with HIV as having sinned.

What are the prevention and care needs in their region?

The majority stated that stigma, prejudice, and homophobia are alive and well in Nebraska. The medical personnel in the rural areas need more education and understanding about HIV, and they are in need of bilingual personnel. This includes RNs, dentists, and mental health providers. It is very difficult for non-English speaking individuals to communicate with medical providers that do not speak Spanish. Medical personnel need to know that "they will not get HIV if they touch me".

It is often difficult to get in the schools to provide comprehensive education about HIV, so there needs to be progress to try to work with churches or other organizations to provide comprehensive sex education. Need to have individuals who are HIV positive go into the schools to talk, so that the kids understand that HIV affects everything in your life, that it is difficult to plan ahead because you don't know if there is a future, or if you will ever have sex again.

What are the gaps and barriers to prevention and care?

The PLWA responded that there is a lack of understanding that so many issues are related to and impact HIV in their lives, but the programs that provide financial assistance sometimes do not understand that. Most of the PLWA feel that there is a lack of knowledge in the medical community about HIV, especially outside of Lincoln and Omaha. The distance that needs to be traveled to access medical care is a barrier to care as well as the lack of medical providers in areas outside of Lincoln and Omaha that will provide services to clients with HIV. An additional barrier is language, when the client does not speak or understand English and the medical provider does not speak the client's language. Interpreters in the rural areas are very difficult to find.

Other barriers identified by the PLWA include education about HIV, how it is transmitted and how to protect yourself from getting HIV. Abstinence Only education does not work. Education about HIV needs to begin early in the schools, churches, or at home. The education needs to include information about alcohol and drugs.

Where did you get your information about HIV/AIDS when newly diagnosed?

Most responded they received education from the counseling and testing site, the physician, the Nebraska AIDS Project, the National AIDS hotline, and books and magazines. Most of the PLWA agreed that once they were diagnosed, getting education was not an issue. However, prior to that time, they found a lack of educational resources. From the perspective of the PLWA, many physicians, as well as emergency room and hospital personnel, lack information about HIV/AIDS and are in need of additional education and understanding about the disease and issues related to HIV.

What changes have the PLWA have seen in the HIV epidemic over the last 20 years?

They responded that there is a better understanding and tolerance toward gay individuals. Nonetheless, there is concern that there is more complacency about HIV since there are medications that are keeping people alive. They are concerned that teens are not too worried about HIV as they have heard about it all of their lives and it is no big deal because the medications are helping people live longer. They are noticing that there are more HIV positive individuals with children, and more HIV positive women, so HIV is more that just a gay disease anymore.

SURVEY OF PEOPLE LIVING WITH HIV/AIDS IN NEBRASKA

The purpose of the People Living with HIV/AIDS survey was to gather information about the quality, accessibility, and availability of services for people living with HIV or AIDS (PLWH/A) in Nebraska. The survey results were intended to help the Ryan White Title II and Title III programs improve services for PLWH/A in Nebraska. Forty-two PLWH/A that attended the 2001 HHS HIV Prevention/Ryan White PLWA Retreat and Conference completed the survey. Most of the survey questions dealt with PLWH/A medical and dental care needs and services.

The following is a brief summary of the questions and responses about medical and dental care needs and services.

- When asked to "describe the overall quality of your medical care", 41 out of 42 persons responded as follows:
  - 14 excellent
  - 9 very good
  - 12 good
  - 4 fair
  - 2 poor

- Seventy percent (28) of the respondents said that an HIV specialist was their primary health care provider and would treat them for conditions other than HIV when necessary. Twenty percent (8) said that a general practice physician acted as their primary care physician. The remaining 10% (5) considered a physician assistant or nurse practitioner, any available hospital or clinic site, or the VA Infectious Disease Clinic as their primary care physician.

- The respondents were asked “how far from your home is your primary health care provider”. Thirty-two responded that they traveled up to an hour. Nine responded that they traveled up to 3 hours

- The respondents rated their primary health care provider’s knowledge of HIV/AIDS treatment, with 14 as excellent, 19 as very good, 8 as good, and 1 as fair.

- The survey asked the PLWH/A where they went for primary dental care, with 14 going to a local private dentist, 7 going to a public health clinic (Creighton Dental School and NHS Dental School), 4 traveled to a dentist more than 20 miles away,
  10 went to UNMC, UNO or the Dental College, and 7 do not seek dental care. The reasons identified for not using a local dentist were: did not feel comfortable with local dentists, could not find anyone knowledgeable enough about my condition, no dentist within 20 miles, and believe refused treatment because of HIV status or ability to pay.

- The PLWH/A were asked what services were needed during the past year, and whether the service was accessed locally or had to travel for the service, or could not get the service. The following table summarizes the responses.

Service	# Needing	# Obtained locally	# Obtained 20 + miles away	# Unable to access
Social Work / Case Management	27	19	4	0
Outpatient Medical Care	28	18	6	1
Home Health Care	8	5	1	2
Hospice Care	2	1	0	0
Pharmacy / Medications	38	22	10	0
Counseling / Support Group	28	13	4	5
Nutritional Services	15	7	0	3
Rehabilitation Services	7	4	0	2
Drug / Alcohol Treatment	6	2	0	1
Child Care	3	0	0	1
Advocacy	13	5	1	2
Emergency Financial Assistance	27	11	2	6
Food Bank Services	18	9	1	3
Housing Services	17	8	2	2
Transportation to Care	16	8	1	3
Legal Assistance	10	4	1	2

- The Persons Living with HIV/AIDS were asked, "*what are the biggest needs, gaps, and barriers for services in Nebraska?*" The needs most often identified include: housing, food, financial assistance for utilities and other living assistance, financial assistance for medical expenses not related to HIV/AIDS, transportation, access to all health related services (medical, dental, medications, vision, mental health), more support groups, help for people that do not qualify for Ryan White, and an end to discrimination related to HIV/AIDS.

- In answer to the question "*what are the biggest gaps in service delivery?*" the PLWH/A reported: discrimination, lack of education about HIV/AIDS, travel distances, housing assistance, mental health services, assistance for medical problems unrelated to HIV/AIDS, adequate financial assistance, assistance for certain minority groups, and communication between HHS and CBO.

- When PLWH/A were asked "*what do you think are the biggest barriers to services that you need?*" responses included: poverty, transportation, travel across large state, lack of services such as mental health, lack of communication, language barrier, lack of knowledge about HIV/AIDS, fear, some church communities, and not enough financial assistance to go around.

- *What types of services do you think the Ryan White CARE Act covers for persons with HIV?* The respondents replied: medications, housing, utilities, transportation, food, medical assistance, any HIV/AIDS related issues, and only for people with a low income.

- The survey asked, "*In the last year have you used any of the following Ryan White CARE Act services?*" There were 29 respondents to this question, and are identified below.

AIDS Drug Assistance Program	9
Housing Assistance	6
Transportation Assistance	9
Mental Health Care	4
Health Care	4
Dental Care	10
Utility Assistance	4
Food Assistance	4
Insurance Premium Assistance	2
Substance Abuse Treatment	0

- How well are people in Nebraska educated about HIV disease? The answers from the PLWH/A survey are identified below.

Very poorly	2	Well	7
Poorly	20	Very well	2
Adequately	9		

- *What types of risky behaviors are people in Nebraska engaging in?* The responses of the PLWH/A survey are identified below:

Oral sex without a latex condom	29
Anal sex without a latex condom	25
Vaginal sex without a latex condom	24
Sharing needles and works	14
Other risk behaviors	4
rimming; not using a condom because it doesn't facilitate enjoyment; feel condoms are not reliable	

- *If there were one thing that the state of Nebraska could do to help prevent others from getting infected with HIV, what would it be?*

  The overwhelming response was education. The survey respondents said that education should be increased in middle schools and high schools and should not be Abstinence Only. In addition to education in the schools, it should be provided in the media and the churches. The education should talk about risk behaviors and how to reduce the risks, and work to reduce the shame and fear associated with HIV and people living with HIV and AIDS.

DEMOGRAPHICS OF RESPONDENTS
N = 42

EDUCATION	
Grade School	2
High School	33
GED	3
Technical Degree	7
College	16
Graduate School	2
No Response	4

AGE	
18 or under	0
19 – 25	0
26 – 35	5
36 – 45	16
46 – 55	9
Over 55	3
No response	9

RACE	
Native American	1
African American / Black	1
Black	1
Hispanic / Latino	2
Caucasian / White	32
Other	1
No response	4

GENDER	
Male	32
Female	6
No Response	4

RYAN WHITE CLIENT SATISFACTION SURVEY

The Ryan White funded programs first joint survey to determine client satisfaction with Ryan White funded services was conducted in the Fall of 2001. The Nebraska Department of Health and Human Services receives funding as a Title II grantee through of the Ryan White CARE Act. The University of Nebraska Medical Center, located in Omaha, and Western Community Health Resources, located in Chadron, receive funding as grantees through the Title III of the Ryan White CARE Act.

Ryan White funded services are those services which are provided by either Title II or Title III. These services include: primary healthcare, dental care, mental health care, substance abuse treatment, home health care, case management services, direct emergency assistance (housing, utilities, etc.), insurance premium payment assistance, transportation, and the AIDS Drug Assistance Program (ADAP).

Both Title II and Title III grantees rely on networks of service providers for statewide service provision. The Nebraska AIDS Project, a Title II and Title III sub-grantee, plays an important role in providing case management for clients infected with HIV disease by providing the linkage to health care and support services. It is important to recognize their efforts in the completion of this report.

Client addresses were submitted from the State Title II program, both Title III programs, ADAP, and Nebraska AIDS Project, then collated by the State Title II Program Manager. Duplicate addresses were reviewed to attempt to send surveys to the most recent client address. It is important to note the transitional nature of clients as evidenced by the high number of unopened surveys returned. This may in itself be an indicator of housing permanency issues experienced by clients.

Five hundred surveys (including 30 surveys translated into Spanish) were sent out to clients statewide. Of these, 88 surveys (17%) were returned unopened and non-deliverable. One hundred twenty-five surveys (25%) were completed and returned. Further broken down, of the 30 Spanish surveys mailed, 9 surveys (30%) were returned unopened and non-deliverable, and 8 surveys (26%) were completed and returned.

Demographically, for those surveys completed, males completed 65% (81) and females completed 31% (39). Four-percent (5) did not indicate a gender preference on the survey. The following is an age breakdown of respondents:

Respondents by Age
N = 125

Age Range	Percentage of Total	Responses
24-30	14.1%	18
31-40	37.6%	47
41-50	26.4%	33
51-60	13.6%	17
61-70	2.4%	3
70+	0.8%	1
Unknown	4.8%	6

Geographically, responses were received from at least 25 Nebraska counties as well as one county in Wyoming and two counties in Iowa. Of the responses received, 42.4% (53) of clients resided in Douglas County and 10.4% (13) resided in Lancaster County. Both Douglas and Lancaster Counties include the major population centers (Omaha/Lincoln) of Nebraska. The following is a breakdown of counties from which responses were received.

Respondents by County
N = 125

County	Responses	County	Responses	County	Responses
Adams	1	Douglas	53	Sarpy	1
Antelope	1	Gosper	1	Scotts Bluff	4
Buffalo	2	Hall	6	Sioux	1
Butte	1	Harlan	1	Thayer	1
Cass	2	Kimball	1	Wayne	1
Cedar	2	Lancaster	13		
Cherry	1	Lincoln	2	Goshen (WY)	1
Dakota	1	Madison	3	Pottawatamie (IA)	2
Dawson	3	Platte	2	USA	9
Dodge	2	Saline	1	Unknown	6

It is important to note that not all clients answered every question, meaning response rates for any one question may not equal the total number (N=125) of responses received. The following is a summary of the data collected.

Medical Care

The questions about medical care centered on proximity to HIV related medical care, the extent clients felt their medical condition and treatment plans were explained to them, client inclusion in decisions about treatment and care, and the extent at which clients felt they were receiving quality care and treatment.

- The majority of clients either agreed (66%) or somewhat agreed (21%) that HIV related medical services were near by and accessible without any trouble. The percentage of clients who disagreed was 13%.

- The majority of clients surveyed (84%) felt their medical condition and treatment plans were explained and understood, with a smaller number of clients (14%) only somewhat agreeing with this statement. The percentage of clients who disagreed with this statement was 2%.

- In terms of the extent which clients felt they were included in treatment and care decisions, the majority of clients (82%) agreed that they were included in decisions, with a smaller percentage of clients (10%) who somewhat agreed with this statement. The percentage of clients who disagreed with this statement was 2%.

- Finally, a large majority of clients (82%) felt they are getting quality care and treatment, with a smaller percentage of clients (15%) somewhat agreeing. The percentage of clients who disagreed with this statement was 2%.

Dental Care

Questions regarding dental care involved access to dental providers, ability to get a dental appointment, and the extent that dental needs were explained and understood.

- Regarding access to dental providers, the majority of clients responding (52%) agreed that dental services were near their home and/or that they could get to them without any trouble. A smaller percentage (13%) somewhat agreed. The percentage of clients who disagreed with this statement was 14%. There were a significant number of clients (21%) who indicated that they did not use dental services or the question did not apply to them.

- The majority of clients reporting (48%) indicated they were able to get a dental appointment without any trouble, with a smaller number of clients (15%) somewhat agreeing to this statement. The percentage of clients disagreeing with this statement was 12.5%. A significant number of clients (29%) indicated that they did not use dental services or the question did not apply to them.

Dental Care (continued)

- For the question regarding the extent that dental needs and care were explained by providers and understood by clients, the majority of clients (58%) indicated that they agreed with this statement. A smaller percentage of clients (10%) somewhat agreed. The percentage of clients disagreeing with this statement was 8%. The percentage of clients who indicated they did not use dental services or the question did not apply to them was 23%.

Nutrition

Questions regarding nutrition centered on the extent that nutritional needs were explained and nutritional services offered, when clients needed help or had questions, and was access to a nutritionist by phone or in a clients home town easy to obtain.

- The majority of clients responding (50%) agreed that nutritional needs were explained and offered as needed. A smaller percentage (23%) somewhat agreed with this statement. The percentage of clients disagreeing with this statement was 10%. The percentage of clients indicating that they did not use nutritional services or the question did not apply to them was 18%.

- For the question regarding the extent that a nutritionist was easily accessible either in their home town or by phone, the majority of clients responding (44%) agreed that a nutritionist was easily accessed, with a smaller percentage (16%) of clients somewhat agreeing with this statement. The percentage of clients who disagreed was 14%. The percentage of clients indicating that they did not use nutritional services or the question did not apply to them was 27%.

Mental Health

Questions regarding mental health revolved around access to information about mental health services, access to mental health services, access to substance abuse treatment, and access to emergency services for mental health/substance abuse issues.

- The majority of clients responding (46%) agreed that they were provided information about mental health services, or if they asked about services their provider talked about these services as part of the client's care plan. A smaller percentage of clients (11%) somewhat agreed with this statement. The percentage of clients who disagreed was 13%. The percentage of clients who indicated that they did not use these services or the question did not apply to them was 30%.

Mental Health (continued)

- The majority of clients responding (43%) agreed that they were able to get mental health services without any trouble in their area. A smaller percentage of clients (10%) somewhat agreed with this statement. The percentage of clients who disagreed with this statement was 9%. The percentage of clients who indicated that they did not use these services or the question did not apply to them was 38%.

- Regarding trouble free access to substance abuse treatment in the area in which a client lives, the majority of clients responding (75%) indicated that they did not use substance abuse services or these services did not apply to them. For clients who did access services, 13% of clients agreed that access was trouble free, with 5% of respondents somewhat agreeing to this statement. The percentage of clients who disagreed with this statement was 7%.

- If clients had a mental health/substance abuse emergency did clients know who and how to contact someone in their area? The majority of clients responding (67%) agreed to knowing who and how to call someone in their area, with a smaller number of clients (15%) somewhat agreeing. The percentage of clients who disagreed with this statement was 7%, while the percentage of clients who answered that they did not use or the question did not apply to them was 11%.

Medications

Questions involving medications revolved around the extent that medication information was explained, the importance of taking medication, resource people available for questions or concerns about medications, filling of medication prescriptions, and the extent to which a client's different health care providers knew of each other and coordinated medication.

- When a client is given a new medication the question was asked if they agreed that their provider or nurse explained what the medicine was for, side effects, and how to take the medicine. The majority of clients responding (78%) agreed that this information is presented to them, with a smaller number of clients (9%) somewhat agreeing to this statement. A small percentage of clients (3%) disagreed and 10% of clients responding did not use this assistance or the question did not apply to them.

- Clients were asked about the importance of taking medicines the correct way, the extent that it was explained to them, and their understanding of the importance of following directions. The majority of clients responding (82%) agreed that this information was explained to them, with a smaller percentage of clients (10%) indicating that they somewhat agreed that this was happening. Less than 1% of clients (1) indicated that they disagreed with this statement. The percentage of clients who indicated they did not use this

- Medications (continued)

- Were clients given a name and phone number of someone to call if they had questions or concerns about their medications? The majority of clients responding (76%) agreed that this information was provided to them, with a small percentage of clients (6%) somewhat agreeing to this statement. Less than 1% of clients (1) disagreed that they were given contact information. The percentage of clients who indicated they did not use or the question did not apply was 7%.

- The majority of clients responding (86%) indicated they had a way to get their medications filled/refilled, with a small percentage of clients (4%) indicating they somewhat agreed with this statement. Equal percentages of clients (5%) disagreed with this statement, or indicated they did not use this assistance or the question did not apply to them.

- For clients who received medications from several different providers for different medical problems, the statement was made that these providers know about each other and coordinate medications. The majority of clients (60%) agreed with this statement, while a small number of clients (4%) somewhat agreed with this statement. The percentage of clients who disagreed with this statement was 6%, with 28% of respondents indicating they did not use different providers or the question did not apply to them.

Other/Special Assistance

Clients were asked about other special needs (translation services, physical/handicap needs, unable to read, etc.) and the extent that these needs were addressed properly and politely by appropriate professionals.

- Of those respondents to this question (N=123), 60% indicated that they did not use these services or the question did not apply to them, and 24% indicated that they agreed that if they had special needs they felt their needs were/would be addressed in a proper and polite way. Finally, 9% of those responding somewhat agreed with this statement, with 7% of respondents disagreeing.

- A question was asked regarding translation/interpretation services and the extent that the translator/interpreter was comfortable to be around. Of those respondents who answered this question (N=122), the majority (74%) indicated they did not use translation or interpretation services, or the question did not apply to them and 18% indicated they agreed that the translator/interpreter was comfortable to be around and acted professionally. Finally, 5% of respondents somewhat agreed with this statement, with 2% of respondents disagreeing with this statement.

Case Management Services

Questions regarding case management services revolved around the services clients received in the past 12 months, the length of time it takes for case managers to return calls, and case manager knowledge about HIV issues and client situations. Clients were also asked about what services were most important to them, and the length of travel to access different services. Finally, clients were asked to share any comments or concerns they may have about medical care, services received, or staff they work with.

- Clients were asked to mark all the services that they had received through a case manager during the past 12 months. The services clients could choose from were utilities, insurance, housing, food, transportation, none, or indicate other services which were not listed. The following is a breakdown of the service provided and the number of respondents reporting they had utilized the service in the past year:

Service Category	# of Clients Utilizing Service
Utilities	32
Insurance	19
Transportation	24
Housing	28
Food	27
No Services	49

- Of those clients who answered other, 13 clients responded: 2 reporting "gas," 4 respondents reported "Dental," and 7 respondents reported "Co-Pay medications." It is important to note that clients were asked to choose *all* of the services they may have utilized, therefore there will be duplication of numbers in instances where clients utilize more than one service.

- Regarding case management services, clients were asked when attempting to contact their case manager, how long it takes for their case manager to return their call. Of those clients responding (N=123), 42% indicated that calls were returned with in ½ day, with 26% reporting calls returned within one day. Further, 5% of respondents indicated calls were returned within one week. Finally, 9% of respondents indicated "other", with 17% indicating they did not use a case manager.

- Clients were asked to assess the knowledge of their case manager regarding HIV issues and the client's personal situation. Of those clients responding (N=120), 64% agreed and 12% somewhat agreed that their case manager knew a lot about HIV issues and their personal situation. Further, 8% of respondents disagreed that their case manager was knowledgeable about HIV and the client's situation, with 17% reporting that they did not use case management or the question did not apply.

Case Management Services (continued)

Of those services available, clients were asked to select from the list of services the top five services they felt were most important to them. They were then asked to rank them from one to five based on the importance they placed on those services currently provided (1 being the most important). The following is a ranking based on the number of clients who ranked the service as the top priority:

1. Way to get HIV medicine
2. Way to get medical/health care
3. Help with medical co-pays
4. Way to get housing
5. Way to get dental care
6. Transportation to medical services
7. Help with utilities and insurance premiums (tie)

The structure of this question makes it difficult to assess the extent individuals view as their priorities when assessed as a group. There were two ways of interpreting this question. First, the aforementioned ranking by the number of individuals who ranked a service category as number one, and the following, which is a ranking based on the number of individuals who ranked services as #1, #2, #3 and so forth:

1. Way to get HIV medicine
2. Way to get medical/health care
3. Way to get dental care
4. Help with medical co-pays
5. Transportation to medical services

The second interpretation only allows for the top five choices. It also does not take into consideration that services may be ranked the highest in more than one ranking, meaning "Way to get medical/health care" may be ranked both second and third, however, the higher ranking is chosen allowing for the second highest ranking (dental care) being selected as #3.

Clients were able to select an "other" category and write in any services which were not available for selection. While some of the written comments were actually provided in the rankings, these are some of the comments written in by clients:

- Help to get a job
- Help with food
- Keeping house clean
- Voucher for medical appointments is great
- Personal support of others in same situation
- Confidentiality
- Rent
- ll services are important for me to see – Thanks!

Clients who must travel to obtain services were asked how far they travel (one way) to a number of services. On the following page is a breakdown per service category indicating the number of miles clients travel to services and the percentage of clients based on the number of responses (N) received.

Miles Traveled for Services

Medical Care (N=113)

<10 miles	**56%**	46- 75 miles	**6%**	151-200 miles	**4%**
10-20 miles	**12%**	76-100 miles	**5%**	201-300 miles	**2%**
21-45 miles	**10%**	101-150 miles	**4%**	300+ miles	**<1%**

Dental Care (N=84)

<10 miles	**70%**	46-75 miles	**4%**	151-200 miles	N.R.
10-20 miles	**13%**	76-100 miles	**6%**	201-300 miles	N.R.
21-45 miles	**6%**	101-150 miles	**1%**	300+ miles	N.R.

Case Manager (N=92)

<10 miles	**58%**	46-75 miles	**8%**	151-200 miles	N.R
10-20 miles	**11%**	76-100 miles	**3%**	201-300 miles	N.R.
21-45 miles	**18%**	101-150 miles	**1%**	300+ miles	N.R.

Drug/Alcohol Treatment (N=12)

<10 miles	**58%**	46-75 miles	N.R.	151-200 miles	N.R.
10-20 miles	**25%**	76-100 miles	N.R.	201-300 miles	N.R.
21-45 miles	**17%**	101-150 miles	N.R.	300+ miles	N.R.

Food Bank (N=32)

<10 miles	**59%**	46-75 miles	**17%**	151-200 miles	N.R.
10-20 miles	**13%**	76-100 miles	N.R.	201-300 miles	N.R.
21-45 miles	**22%**	101-150 miles	N.R.	300+ miles	N.R.

Support Group (N=54)

<10 miles	**57%**	46-75 miles	**4%**	151-200 miles	N.R.
10-20 miles	**4%**	76-100 miles	**4%**	201-300 miles	N.R.
21-45 miles	**31%**	101-150 miles	N.R.	300+ miles	N.R.

Mental Health (N=41)

<10 miles	**61%**	46-75 miles	**7%**	151-200 miles	N.R.
10-20 miles	**15%**	76-100 miles	**2%**	201-300 miles	N.R.
21-45 miles	**12%**	101-150 miles	**2%**	300+ miles	N.R.

Other Social Services (N=17)

<10 miles	**35%**	46-75 miles	**6%**	151-200 miles	N.R.
10-20 miles	**41%**	76-100 miles	N.R.	201-300 miles	N.R.
21-45 miles	**18%**	101-150 miles	N.R.	300+ miles	N.R.

Other-List Services (N=1)

35 Miles to Chiropractor

The final portion of the Client Satisfaction Survey asked clients to rate, on a 1 to 3 scale (1=Always, 2=Sometimes, and 3=Never), how clients viewed their experiences interacting with their primary care doctor, staff nurse, physician's assistant, office staff receptionist, lab staff, pharmacy staff, case manager, dentist, and mental health provider. Due to the complexity of the matrix utilized for analysis, it is difficult to summarize findings in the aggregate for each category.

- Generally, clients responded strongly in a favorable manner regarding their treatment and interactions with service providers.

Finally, clients were given the opportunity, in two separate questions, to share any additional comments/concerns they may have about their medical care, services they receive, or staff who work with them.

Summary

The 2001 Nebraska Ryan White "All Titles" Survey presented clients with the opportunity to provide feedback on their perception of satisfaction with services offered by Ryan White Titled entities and funded agencies in the State. One hundred twenty five clients chose to utilize this opportunity.

Generally, clients responded favorably to those services provided by Title II, Title III, and the AIDS Drug Assistance Program. Some issues brought out by consumer comments revolve around access to care and support services as well as access to information and knowledge about the services available through Ryan White. Some issues may be improved through communication about services through case management, however some services, such as access to medical care in remote areas, may only be partly resolved due to the cost of providing access to services to limited numbers of clients in these areas.

Finally, the next consumer satisfaction survey was conducted in CY 2003 and focused on issues of concern brought out through this survey. The construction of the survey tool should be refined to allow for easier tabulation of results through automated means.

HOUSING SURVEY OF HIV POSITIVE PERSONS

The Nebraska Health and Human Services HIV Prevention / Ryan White Program completed a housing survey in early 2002. A total of 360 surveys were distributed to HIV positive persons through the Nebraska AIDS Project (NAP), the Ryan White Title III clinic at UNMC, and the Charles Drew Health Center. Of the 215 surveys that were returned, almost all respondents cited housing problems at some point during their infection. It was disturbing to find that 39%, or 84 persons, report having been homeless at some time since their positive diagnosis. In addition, 67% reported that within the last 12 months some type of housing assistance, problem, or need existed. Urban or rural residency had no impact on this report.

The tables below indicate the numbers of responses to the question "During the last 12 months, have you resided in or experienced any of the following situations":

Needed assistance with heat or utilities	70
Needed assistance to prevent homelessness	59
Moved in with friends or relatives	50
Let other move in to help with expenses	41
Sold car / belongings to pay expenses	39
Lived in transitional housing	4
Hospitalized with HIV / AIDS related illness	32
More than one night in car or on street	11
Harassed by neighbors - moved	15

Faced eviction	33	Phone service cut off	47
Heat / utilities cut off	30	Experienced abuse	15
Moved; couldn't pay rent	21	In jail or prison	12
In emergency shelter	9	In substance abuse facility	7
In psychiatric facility	13		

- Focus groups of NAP case managers, held in January 2002, revealed 90% of their cases could have benefited from some type of housing and utility assistance. The 2001 PLWA Survey, completed by the Ryan White Title II program, documented 40% of the 42 responding needed specific housing services. Both groups further reported it could take from four months to several years to qualify for disability coverage leaving many consumers in abject poverty. Housing authority surveys confirm it takes from two months to 18 months, in some areas, to acquire Section 8 or public housing in the urban areas and from 4 weeks to one year in the rural areas. Both professionals and consumers report it is difficult to acquire and maintain stable housing due to the following documented barriers: lack of low income housing stock, high utility costs, transportation issues, budgeting by consumers, poor choices by consumers, mental health issues, and barriers to access to services due to limitations of case management staffing patterns. The PLWA Housing survey revealed that only 53% actually had a functioning car. This is not surprising given the income levels reported: 67% below $1000 per month, 28% below $500 per month, and 44% with SSDI or SSI as their only income source. This has multiple impacts on the 33% of respondents reported living and/or supporting family units.

Data compiled statewide by NAP case managers based on their case load as of April 2002 (541 clients) revealed the following:

- clients homeless or near homeless – 35%
- clients referred to homeless shelters or transitional housing – 21%
- clients needing rental assistance to maintain housing – 38%
- clients needing utility assistance – 34%
- clients needing transportation – 32%
- client had a mental health diagnosis – 31%
- average client income per month – $662.

The data collected paint the beginning of a clear, but not comprehensive, picture of needs:

- Housing options across the state are desperately needed with a combination of short and long-term options. Long-term may be a better option for the more rural areas. National documented data estimates set the preliminary numbers at 15% or 86 PLWA/HIV and 25% or 131 PLWA/HIV, for a total of 217 needing assistance in a 12-month period. Preliminary data shows these estimates to be low.
- Transportation and access to mental health services are limited due to the huge expanse of the rural areas.
- Housing resources are limited, and to some extent, “hidden” from consumers.
- PLWA/HIV need information, stability, and the ability to make good choices in their personal and living situations to ensure consistent health care across time.
- A complete assessment involving a broad spectrum of stakeholders with an outcome of a long-term housing plan is needed to ensure all providers are on the same page.

NEBRASKA HIV/AIDS HOUSING PLAN

In 2003, AIDS Housing of Washington completed a Nebraska HIV/AIDS Housing Plan for the Nebraska Department of Health and Human Services. The Nebraska HIV/AIDS Housing Plan is the culmination of a nine-month planning process that brought together a wide range of community stakeholders to consider and plan for the housing needs of Nebraskans living with HIV/AIDS and their families. Housing and services providers, people living with HIV/AIDS, and others statewide participated in the needs assessment process and provided input and feedback on the Nebraska HIV/AIDS Housing Plan.

Given the dynamic nature of HIV disease and other factors that affect HIV/AIDS housing planning, it is essential to regularly reassess the needs of people living with HIV/AIDS and the most appropriate strategies to meet those needs. It is intended that the plan be built upon, revised, and expanded as current objectives and new gaps and needs emerge.

Community Participation in the Needs Assessment Process

The Nebraska Department of Health and Human Services convened the needs assessment and planning process and invited a broad range of community stakeholders to participate. A Steering Committee was formed in February 2003 to oversee and guide the needs assessment and planning process. The committee was comprised of people living with HIV/AIDS and representatives from community-based organizations that provide housing and services to people with low incomes and/or special needs.

In addition to participating in Steering Committee meetings, people living with HIV/AIDS participated in the needs assessment process through a housing survey and consumer focus groups. In 2002, a total of 215 people living with HIV/AIDS completed a housing survey that posed questions about individuals' housing histories, needs, and preferences. People living with HIV/AIDS from around the state participated in focus groups, which allowed participants to discuss their housing situations, needs, and preferences in more detail than the survey had allowed.

Interviews were held with key stakeholders from throughout the state, including case managers, housing and services providers, housing developers, government representatives, clinical social workers, medical providers, and other concerned community members, including members of the Steering Committee. These stakeholders were identified as those most knowledgeable, as well as able to provide leadership on related issues in the future.

The Context of HIV/AIDS Housing in Nebraska

As medical advances are helping people with HIV/AIDS live longer lives, there are now more people living with HIV/AIDS - who are particularly in need of related assistance - than ever before.

At the end of 2002, a total of 1,112 Nebraskans were living with HIV/AIDS, including 557 people living with AIDS and another 555 people living with HIV who had not been diagnosed with AIDS. People of color are disproportionately impacted by HIV/AIDS in Nebraska, particularly African Americans. Compared to just six percent (6%) of the state's population, almost one-quarter (24%) of those living with HIV/AIDS are African Americans. Increasingly, younger people are affected by HIV/AIDS. While less than one-quarter of those living with AIDS are under 30 years old, 40% of those living with HIV are in this age group.

People living with HIV/AIDS in Nebraska experience many of the same challenges as other Nebraskans, especially those with low incomes. These difficulties include finding affordable, good quality housing, overcoming geographic barriers to access medical care, services, and employment, and limited employment opportunities in many areas.

Many people have difficulty paying housing costs. More than a quarter of those who responded to the housing survey had incomes less than $500 per month, which is below poverty level. Slightly more than one-third of respondents were "severely housing cost burdened," paying more than half of their income for housing, while just 12% had regular assistance paying their housing costs. In addition, 15% had faced eviction in the past year and 39% had been homeless since testing positive for HIV.

Across Nebraska, many people living with HIV/AIDS continue to hide their health status in fear of the negative impact disclosure may have on their families, employment, health insurance, housing, and physical safety. This affects the willingness of people living with HIV/AIDS to reach out for support and assistance, especially people living in smaller communities, rural settings, and culturally based communities.

There are two major federal programs dedicated to serving the needs of people living with HIV/AIDS that can be used for housing. The Housing Opportunities for Persons with AIDS (HOPWA) program administered by the U.S. Department of Housing and Urban Development (HUD) is the primary source of funding dedicated to meeting the housing needs of people living with HIV/AIDS. Nebraska is not eligible to receive a formula allocation of HOPWA funds because less than 1,500 cumulative cases of AIDS have been reported statewide. However, in June 2003, the Nebraska Department of Health and Human Services partnered with the Nebraska AIDS Project and other community stakeholders to submit an application for HOPWA Competitive Funds, which proposed a range of housing initiatives. In February 2004, the Nebraska Department of Health and Human Services was awarded $1,357,192 for the Health Empowerment Acquired Regionally Through Housing (HEARTH) project. The HEARTH project will serve clients statewide by providing direct housing assistance, comprehensive case management, mental health services, transportation, and housing information services. This is the first time Nebraska has received this Housing Opportunities for Persons with AIDS (HOPWA) grant.

Nebraska receives funding dedicated to serving people living with HIV/AIDS from the U.S. Department of Health and Human Resources and Services Administration's (HRSA) Ryan White CARE Act. Although these funds allow for the provision of many valuable services, they alone cannot and should not be the sole source of support for people living with HIV/AIDS.

Data compiled by the Steering Committee on critical issues in housing people with HIV/AIDS revealed the following:

1) Stigma and discrimination seriously impact access to housing
   - the fear of being stigmatized affects individuals' willingness to access needed services
   - there is a lack of understanding on the part of some service providers of the need for and importance of confidentiality related to HIV and the impact that fear of disclosure has on the willingness of people living with HIV/AIDS to access services for which they may be eligible
   - fear of HIV/AIDS on the part of service providers and community members impacts the ability of people living with the disease to access jobs, housing, and services
   - the lack of community education about HIV/AIDS impacts the acceptance of people living with the disease
   - gay, lesbian, bisexual, and transgender Nebraskans experience stigma and discrimination based on their sexual orientation, regardless of their HIV status

2) Lack of appropriate affordable housing options
   - there is a lack of affordable, safe, decent, and appropriate housing that limits access to the full continuum of housing options for people living with HIV/AIDS
   - there is limited funding available to support the creation and maintenance of needed programs
   - housing providers and HIV/AIDS service providers need to increase collaboration
   - people living with HIV/AIDS and service providers need more information about and awareness of available housing options

3) Access to and availability of all necessary support services
   - the housing and related service needs of people living with HIV/AIDS have changed and expanded as people are living with the disease
   - it is challenging to meet the needs of an increasingly diverse population of people living with HIV/AIDS
   - not all clients understand the role of case managers and that through accessing case management support their needs are more likely to be anticipated and met to avoid crisis
   - linkages between housing and all necessary support services are lacking for many people living with HIV/AIDS, including both those in need of housing and those who are housed
   - there is a lack of transportation options for people in both urban and rural areas of the state
   - a lack of medical, dental, and case management services to adequately address the global needs of persons living with HIV/AIDS was identified

4) Financial issues for people living with HIV/AIDS
    - due to the physical challenges faced by people living with HIV/AIDS and the inability of many to maintain employment, poverty is a significant barrier to obtaining and maintaining adequate housing and accessing needed services and information
    - some people living with HIV/AIDS have high medical expenses, which impacts their financial situation and credit rating and subsequently limits their access to certain housing options
    - people living with HIV/AIDS and service providers need more information about and awareness of training and employment opportunities available to disabled persons

Strategies were developed to address the critical issues described above. They are as follows:

<u>Stigma and Discrimination Seriously Impact Access to Housing</u>

- Educate community stakeholders about HIV disease and the impact of HIV/AIDS in Nebraska in order to increase awareness and acceptance of people living with HIV/AIDS and to dispel myths about HIV/AIDS and Nebraskans who live with the disease.
- Increase housing stability and access to housing resources for people living with HIV/AIDS by educating them about fair housing laws and standard operating procedures of housing authorities as they relate to confidentiality and the disclosure of disability status. Explore and develop strategies to ensure people living with HIV/AIDS have the information they need about their housing rights in order to avoid experiences of discrimination in housing.

<u>Lack of Appropriate Affordable Housing Options</u>

- Increase affordable housing units accessible to people living with HIV/AIDS.
- Increase opportunities for emergency housing solutions generally and improve access to assistance for persons living with HIV/AIDS.
- Increase housing stability and access to housing resources for people living with HIV/AIDS through education.
- Develop a comprehensive listing of HIV/AIDS services available in Nebraska, including eligibility criteria and contact information. Increase awareness of programs and guidelines by widely distributing this listing to housing and service providers throughout the state. Make the material available in forms and locations such that people could access relevant information without disclosing their HIV status.

<u>Access to and Availability of All Necessary Support Services</u>

- Educate people living with HIV/AIDS about the services available through the HIV/AIDS service system and the other services systems in the state.
- Advocate for additional case management services for people living with HIV/AIDS in order to increase the support available to each client through this system.
- Explore opportunities to develop a comprehensive peer-to-peer mentoring program to assist people living with HIV/AIDS to access housing and services and to provide peer support to those living with the disease.
- Increase resources available to people living with HIV/AIDS who have mental health and/or substance use issues by maintaining and enhancing linkages between AIDS service providers and mental health and substance use treatment providers.

- Increase access to appropriate services for people who are monolingual (in a language other than English) by ensuring the availability of translated materials and access to translators. Increase volunteerism among people who are bilingual. Maintain and enhance linkages between AIDS service providers and agencies currently serving monolingual populations.
- Develop additional transportation options in order to increase access to medical and support services for people living with HIV/AIDS.
- Increase the availability of support services to people living in rural areas of the state.

Financial Issues for People Living with HIV/AIDS

- Enhance economic opportunities for persons living with HIV/AIDS to support housing stability. Develop and enhance linkages between AIDS service providers and employment and job training programs in Nebraska, including Vocational Rehabilitation, Workforce Development, and the Ticket-to-Work program.

The implementation of effective initiatives and programs relies on increased community knowledge, successful partnerships, and continued assessment and planning. The stakeholders involved in this process have an ongoing commitment to addressing all the identified needs through further action planning, increased collaboration and partnerships, and securing new sources of funding to support programs.

STATEWIDE COORDINATED STATEMENT OF NEED (SCSN*)*

The purpose for the development of a Statewide Coordinated Statement of Need in Nebraska is twofold:

1. To increase the effectiveness in serving persons with HIV disease in Nebraska through the three Ryan White funded entities in the state by identifying common unmet needs and barriers to receiving services.

2. To increase and improve coordination of services provided to persons and their families living with HIV disease. The process for accomplishing this purpose is based on current HIV and AIDS epidemiological information, information collected from consumers, and data compiled from services provided by Ryan White Funded entities in the State.

The Statewide Coordinated Statement of Need, completed in 2001, identified gaps and barriers, whether real or perceived, to service delivery for persons living with HIV and AIDS (PLWH/A). *The following are the gaps and barriers identified and listed in order of priority.*

Geographic Distance to Providers

- For individuals living in rural areas, access to health care and support services can involve several hours of travel. HIV medical specialists are predominantly in the eastern part of the state.

Affordable Health Care

- Chronically ill individuals often lack sufficient employment to maintain health insurance. For the unemployed, options are limited to Medicaid / Medicare, COBRA, or Ryan White funded services. Ryan White does not cover in-patient care.

Lack of Health Care Providers

- Especially in rural parts of the state, there is a lack of primary care providers, dentists, and mental health professionals willing to treat HIV positive individuals.

Lack of Mental Health/Substance Abuse Services

- Insufficient services available, especially in rural areas.

Lack of Affordable Housing

- Low-income housing is scarce in rural areas. Lack of resources and programs for qualified individuals to access housing in smaller municipalities. Fear of disclosure of HIV status to landlords or neighbors.

Confidentiality

- Both clients and case management providers acknowledge that confidentiality of a client's request involves disclosure of status. This is especially evident in small towns where communities are close knit and residents know each other. Confidentiality concerns are also expressed in a client's decision to access health care outside of his/her community for fear of disclosure of status.

Lack of Transportation

- Public transportation services are limited in both urban and rural areas.

Access to Medications

- Clients taking medications are limited to formulary restrictions when accessing ADAP, which may not be adequate for client's particular medical condition. Clients covered by Medicaid or private insurance are faced with co-pays.

Lack of Income/Back to Work Issues

- Clients who are chronically ill lack financial resources to maintain self-sufficiency and often have to depend on family, friends, human services, and government for assistance. There is also a lack of educational and job-training opportunities for individuals who want to re-enter the work force.

Lack of Accessible Case Management Services

- Clients often must travel to access case management, especially in rural areas of the state.

Lack of Knowledge Regarding the Availability of Ryan White Services

- There is a lack of information available to clients about case management and Ryan White services.

The future focus of Statewide coordination on the basis of identified gaps and barriers in care and services to individuals infected with HIV disease are represented in broad statewide goals.

Increased Access to Care

- Increase the number of service providers with emphasis on rural settings where the need is greatest. With Nebraska being a predominately rural State with a low population base there will always be a "distance" factor between clients and services. Increasing transportation availability and options to clients will also improve access to care.

Affordable Healthcare

- Provide access to affordable healthcare consistent with current treatment guidelines through coordination of healthcare services between Titles as well as providing assistance to clients in maintaining health insurance as well as providing assistance to clients who qualify for services through Medicaid or Medicare.

Affordable, Safe Housing

- Improve access to affordable, safe housing through coordination and referrals for qualified clients to state and local housing authorities. Pursue funding through "Housing Opportunities for People With AIDS" (HOPWA) to provide additional funding and case management for housing issues.

Access to Medications

- Increase access to a broad range of medications to treat HIV and related illnesses. Coordinate funding between Titles to maximize the variety and amount of medications available to clients. Guarantee access to medications for current clients through utilization of additional funding streams to include State funding and ADAP supplemental funding.

Access to Case Management

- Continue to jointly fund case management services increasing access where appropriate with available funding. Provide information to case managers regarding the variety and availability of services for eligible clients. Provide training where necessary to case managers regarding new information, processes or procedures.

Evaluation and Quality Management

- Improve evaluation efforts through joint planning and evaluation where appropriate (i.e. needs assessments, satisfaction surveys). Utilize joint data collection where appropriate and share data between entities. Implement case management standards as a basis for evaluation of case manager performance and to identify emerging issues in case management. Utilize case management software for data collection and sharing of data between Titles (with appropriate releases in place).

In addition to those gaps and barriers identified previously, emerging issues, which are or will impact Ryan White funded entities in the future, are identified.

Continued Funding for CARE Act Supported Services

- As noted in FY 2001 appropriations, especially in the area of ADAP, Federal funding is not keeping pace with the increase in new ADAP clients. In addition, the cost of HIV therapeutics continues to be high.

Increase in Minority Participation in Ryan White Funded Programs

- The increase of minorities in need of services, to include Hispanic and African immigrants/refugees, Native Americans and migrant workers. Support services which are culturally sensitive and language appropriate are needed. Additionally, services available to citizens and legal immigrants may not be available to individuals who are undocumented, presenting additional issues concerning healthcare, housing, and other forms of governmental assistance.

Funding for Hepatitis C Medications

- Increasing numbers of HIV/HCV co-infection and the development of treatment regimens for HCV put pressure on ADAPs to cover these medications which are more expensive than current HIV treatment regimens. Alternate funding sources are needed to assist this emerging population for treatment and medications, which are limited through Ryan White funded entities.

Rural versus Urban Issues

- The issues specific to clients living in rural versus urban areas of the state need to be identified. Frequently, the financial cost to support a client in a rural area is more than that of a client living in an urban area. Increasing numbers of rural clients require the identification of area specific issues, increased funding and services located locally, or at a minimum regionally.